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Social integration in a reversed integration neighbourhood?

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Chapter 7

General discussion

7.1 Summary of the main findings

The overall aim of this research was to get a better understanding of the perspectives of the different stakeholders in the integration process of people with intellectual disabilities in the reversed integration neighbourhood, and of the role of the formal and informal support in enhancing social integration of people with intellectual disabilities. To acquire such knowledge, a multidisciplinary approach was used. First, interviews were held to increase our knowledge about the perspectives of neighbours, family members of people with intellectual disabilities, and DSPs in a reversed integration neighbourhood. Second, based on quantitative data and an expert meeting the role of formal and informal support in enhancing social integration was determined.

Different Perspectives

In several studies, the perspectives of one of the stakeholders (neighbours, family members and DSPs) regarding integration of people with intellectual disabilities has been investigated in integrated settings (van Alphen et al., 2012; Bigby et al., 2009; Lundebj, 2010; McConkey & Collins, 2010; Robertson et al., 2005). Reversed integration has hardly been investigated (Bos, 2015), whereby the perspectives of the different stakeholders in these settings were not mentioned.

In the literature about integrated settings, several factors were found that negatively influenced the attitudes of neighbours towards integration. One such factor is having young children (Schwarz & Rabinowitz, 2001); moreover, the presence of a large number of people with intellectual disabilities in the neighbourhood, as well as the presence of people with severe or profound intellectual disabilities and people with behaviour and/or psychiatric problems negatively influence the attitude of neighbours (van Alphen et al., 2012). In the reversed integration setting in our research, the majority of the people with intellectual disabilities were people with severe or profound intellectual disabilities or with behaviour and/or psychiatric problems. This would suggest a negative attitude of neighbours in these settings. However, as in these neighbourhoods people without intellectual disabilities have freely chosen to come and live on the grounds of a formal residential facility where people with intellectual disabilities still live, we expected that the neighbours in

reversed integration neighbourhoods would have a positive attitude regarding social integration of people with intellectual disabilities.

The perspective of family members regarding integration has hardly been investigated. To our knowledge, one study has focussed on this subject and they found a positive attitude (Tøssebro & Lundebj, 2010). This result would suggest that the family members in a reversed integration neighbourhood would also be positive. Finally, DSPs in integrated settings gave no priority to the social integration process of their clients (McConkey & Collins, 2010). Their first priority was providing proper care. Moreover, DSPs believed that social integration of people with intellectual disabilities and high support needs was not possible because of the severity of the disabilities (Bigby et al., 2009). DSPs working in a reversed integration neighbourhood have to deal with a new and unpredictable environment. At the same time, however, in reversed integration the neighbourhood is adapted to the people with intellectual disabilities and therefore, the expectation is that DSPs in this setting are more positive about integration of people with intellectual disabilities compared to the DSPs in integrated settings.

In the present research several noteworthy differences were found in the perspectives of the stakeholders regarding integration of people with intellectual disabilities (see chapter 3). The neighbours living in a reversed integration setting expressed an overall positive attitude, while previous research findings within an integrated setting showed a negative attitude of neighbours towards integration of people with intellectual disabilities (van Alphen et al., 2012). Neighbours living in a reversed integration setting did not seem to be bothered by the presence of a large number of people with high support needs. This finding is in line with the study of Robertson et al. (2005) showing hardly any negative argument mentioned by the neighbours regarding integration of people with intellectual disabilities in the community. In the present dissertation, the perspectives of family members were diverse, but largely influenced by the severity of the intellectual disabilities and the level of behaviour and/or psychiatric problems. Family members who had a relative with a severe or profound intellectual disability or a relative with a high level of behaviour and/or psychiatric problems, overall had a negative or reserved attitude regarding integration. The reversed integration neighbourhood caused restrictions in freedom of movement and the people with high support needs did not have contact with the neighbours according to these family members. The perspectives of family

members in our study are not in line with the study of Tøssebro and Lundebj (2010). However, one explanation could be that in their study more people with mild and moderate intellectual disabilities were involved.

Concerning the DSPs, they had a reserved perspective regarding integration of people with intellectual disabilities. 50 Percent of the DSPs were negative or neutral and even 43 percent of the DSPs who were predominantly positive about integration, mentioned some negative arguments. Similar to the family members, they argued that integration led to restrictions in freedom of movement and that integration was not possible for people with high support needs. Moreover, there were no differences found between the attitudes of DSPs who worked in an integrated setting and DSPs who worked in a reversed integration neighbourhood. The opinion of DSPs concerning integration of people with high support needs in this present research is in line with the study of Bigby et al. (2009). DSPs believed that these people are too different and their disabilities too severe to become integrated in the community.

Another important finding is that especially the DSPs have opinions about the perspectives of the other stakeholders (i.e., meta-perspectives; Vorauer, 2013) which do not correspond with the actual perspectives of those stakeholders. Overall, the DSPs expected that others had a more negative perspective on integration of people with intellectual disabilities than was actually the case. Especially for the neighbours the DSPs underestimated their interest in contact with people with intellectual disabilities and more generally in the integration of these people.

Our research also revealed that the attitude of the DSPs towards integration is largely influenced by their concerns with respect to safety (see chapter 2). In the first place, DSPs feel responsible for the safety of people with intellectual disabilities, but also for the safety of the neighbours and themselves. The work of the DSPs consists to a large extent of keeping control of the situation and guaranteeing the safety of all peoples involved (McConkey & Collins, 2010). Our data reveal that these feelings of control are threatened in situations where people with and without intellectual disabilities share public space as is the case in reversed integration settings.

Role of formal and informal support

Several studies have already shown that DSPs play an important role in enhancing social integration of people with intellectual disabilities (van Alphen, 2011; Chowdhury & Benson, 2011; Mansell, 2006; Mansell et al., 2002; Overmars-Marx,

2011). Our own research is fully in line with these findings; in fact, we found that the DSPs play a key role in the social integration process. First of all, they have a key role in the physical and social integration of people with intellectual disabilities: their contribution is irreplaceable for initiating and facilitating contact between people with and without intellectual disabilities. Second, they are important in the utilisation of volunteers in enhancing social integration.

The actual effort that the DSPs invest in accomplishing their role in the social integration process is determined by several psychological variables. In the present research we found that their attitude towards integration of people with intellectual disabilities, their experienced competencies, their professional identity and their meta-evaluation (i.e. their thoughts about how the other stakeholders would evaluate them and their work) were directly influencing their effort to facilitate social integration (see chapter 4). The relevant social norms (i.e. DSPs' beliefs about the opinion of the other stakeholders regarding social integration) were indirectly determining the effort of DSPs via their attitudes. Our results are in line with the Theory of Planned Behaviour (Ajzen, 1985). This theory explains the behavioural intentions in a specific context. Moreover, in the studies of Rise et al. (2010) and Marta et al. (2014) was already suggested to add identity to the Theory of Planned Behaviour. The results of this research support their suggestion. Besides, based on this research, in addition – and closely related – to social norms, meta-evaluation (Vorauer, 2013) may also be a valuable addition this theory.

The role of informal support (through volunteers and family members) in enhancing social integration was, nationally and internationally, not yet investigated. The present research (see chapter 5 and 6) primarily focussed on volunteers, because it is uncertain how much more family members can support their relatives, especially in the social integration process (Brouns, Tap & Stam, 2013; Oudijk, de Boer, Woittiez, Timmermans & de Klerk, 2010). We found that the volunteers already play a role in the physical integration of people with intellectual disabilities. Placing them physically in a context where they also come across people without intellectual disabilities, is the first step to social integration. However, volunteers are often unaware of their role in enhancing social integration of people with intellectual disabilities, whereby their role is not optimal utilised. This also implies that they are not informed about and supported in activities concerning this topic.

In regards of the recruitment of volunteers, in the current society people who want to become a volunteer, have different aims when compared to the traditional volunteer work. Traditionally, the volunteers offered their services on a long term basis and with altruistic motives (Hustinx, 2011; Scholten, Meeuwssen & Berman, 2011; Wardell, Lishman & Whalley, 2000). Nowadays people prefer doing short term volunteer work, in which there is no enduring commitment to a specific organisation (Dekker, de Hart & Faulk, 2007; Hustinx, 2011). Moreover, their motivation to start with volunteer work is more often to learn new skills and acquire work experience (Wardell et al., 2000).

In this research we found that volunteer work in the support of people with intellectual disabilities was still primarily performed by traditional volunteers, i.e., women with an average age of 55 years who did not have a paid job or were retired. Moreover, the policy and recruitment were still focussing on the traditional volunteers. If nothing changes, a shortage of volunteers may arise because of ageing of the current group of volunteers (Scholten, Meeuwssen & Berman, 2011) and because of a stagnation in new volunteers. This could be a risk for the social integration process of people with intellectual disabilities because first of all, volunteer work in itself enhances social integration. Second, as mentioned above, volunteers play an important role in the physical integration of people with intellectual disabilities. Together with the fact that DSPs have less time to take their clients into the community (Hatton et al., 1999; Hermsen, Embregts, Hendriks & Frielink, 2011; Kowalski et al., 2010), a shortage of volunteers may result in less opportunities for people with intellectual disabilities to become socially integrated.

7.2 Methodological reflections

The present research was executed in one organisation in the support of people with intellectual disabilities, which is situated in northern part of the Netherlands. Nevertheless, we feel safe to assume that the findings are by and large generalizable to other organisations in this field. First of all, we worked with a large organisation in which a large number of people with intellectual disabilities live and/or work. Moreover, the level of intellectual disabilities ranged from mild to profound intellectual disabilities and there was also a substantial group of people who had, besides their intellectual disabilities, behavioural and/or psychiatric problems. Because of the large number of clients, the number of DSPs was also high. Moreover, in this organisation

all types of locations for people with intellectual disabilities (i.e., residential facility, reversed integration neighbourhood, community houses) were represented and incorporated in this research. Together this created representative groups of DSPs and volunteers. All the DSPs and volunteers who were working in the residential facility and the reversed integration neighbourhood were invited to participate. Moreover, community houses from two different places were incorporated in this research. In total, 927 DSPs and 238 volunteers were approached in this research.

A problem in the present research is that the response rates, especially for the group of DSPs, who had to participate during their working hours, was relatively low. First of all, the participants might have been unwilling to participate in the research. DSPs already experience high work pressure and shortage of time (Hatton et al., 1999; Hermesen et al., 2011; Kowalski et al., 2010). Therefore, participating in research may not have high priority for them. Besides, during the research there has also been a natural turnover of staff. The effects thereof are unclear. Regarding the other stakeholders (family members and neighbours), there could have been a selection bias. For example, family members may have used the research in order to express their dissatisfaction or to achieve changes. Conversely, only neighbours with very positive attitude might have agreed to participate while many other neighbours might have had no interest in being part of this research. However, as in the present research hardly any family member refused to participate, and neighbours all agreed to participate when asked, the chance of selection bias seems to be very small.

A strength of the present research is the use of qualitative as well as quantitative research methods. Reversed integration is a relatively new topic of research and the usage of both methods gives generalizable but also in-depth knowledge about reversed integration. Quantitative data was collected with newly developed instruments. Concerning the psychometric properties, we determined the reliability of the DSP questionnaire regarding integration. The reliability of the different scales in the questionnaire were proven to be good or very good ($\kappa > .70$), nevertheless, so far we have no data concerning the validity of this questionnaire in other samples. To collect qualitative data, interviews were held and an expert meeting was organised. To analyse these data, we used an explorative analysis (open coding) to get as much information as possible. Subjectivity in coding is a risk, which we tried to prevent by measuring the inter-rater reliability. The outcomes of the reliability were substantial (Cohens Kappa=.78) to very good/almost perfect (Cohens Kappa= .85

and .93) (Landis & Koch, 1977). Another point of discussion is that in collecting qualitative data, a fixed sample size was used. It is unclear if data saturation was actually reached. Nevertheless, the sample size was based on the ideal sample size for phenomenological research (Creswell, 2007).

7.3 Theoretical reflections

As stated in the introduction, in this research we focused on social integration of people with intellectual disabilities in reversed integration neighbourhoods. Social integration was defined as being part of a broader community in which the person with intellectual disabilities is appreciated and respected (van Alphen, 2011; van Gennep & Ruigrok, 2002).

Apart from social integration, in scientific literature several other terms are also used to describe the process in which people with intellectual disabilities become part of the community, for example community integration, non-segregation, and inclusion (e.g. van Alphen, 2012; Bigby et al., 2009; Carnaby, 1998; Cummins & Lau, 2003; den Daas et al., 2007; van Gennep & Ruigrok, 2002; Thorn et al., 2009). In the present research we chose to use the term social integration because it includes physical integration – the mere presence of people with and without an intellectual disability in the same environment - as well as actual social contacts (van Alphen et al., 2010; Bos, 2015; Carnaby, 1998; Cummins & Lau, 2003; den Daas et al., 2007; van Gennep & Ruigrok, 2002; Thorn et al., 2009)⁵. Moreover, compared to the implications of the term social inclusion, the expectations and demands regarding social integration are less high. Based on the literature, inclusion encompasses access to community services and facilities, being part of a social network, having a sense of belonging, being accepted, and performing social roles in the community (Corbigo, Ouelette-Kuntz, Lysaght & Martin, 2008; Overmars-Marx, Thomése, Verdonschot & Meininger, 2013; Thorn et al., 2009). Inclusion appears to be the ultimate goal in policy and research concerning people with intellectual disabilities

⁵ An exception is chapter 4, in which we do refer to attitudes towards inclusion as main dependend variable. Nevertheless, inclusion is in this study defined as an equivalent of integration (Clement & Bigby, 2009). Importantly, this assumed conceptual equivalence holds in the orthopedagogical context, but not to the same extent in the social-psychological literature. Here, context recent definition of inclusion is: “the degree to which an individual perceives that the group provides him or her with a sense of belonging and authenticity” (Jansen, Otten, Van der Zee & Jans, 2014). Hence, the focus is much more on the psychological experience of inclusion, which makes the concept not an equivalent to integration, but rather a sub-component, which is most closely related to what has been described as psychological integration (de Vroome & Verkuyten, 2015).

(Chowdhury & Benson, 2011; European Intellectual Disability Research Network, 2003; Schalock, Bonham & Verdugo, 2008; Thorn et al., 2009). However, our research has shown that most stakeholders find it doubtful whether social inclusion in this sense is achievable for people with intellectual disabilities and high support needs (Clement & Bigby, 2011). Rather, it seems more effective and realistic to concentrate on the steps that need to be taken to accomplish physical integration and social contacts.

The first step to social integration is being present in the community, i.e., physical integration (van Alphen, 2012; van Gennep & Ruigrok, 2002). This does not only include the location of living arrangements, but also being physical in the community so that people with and without intellectual disabilities could see and hear each other. The next step is actual social contact between the people with intellectual disabilities and their neighbours or other people in the community; importantly, such social contact may involve only minimal interaction, such as greeting each other.

Nonetheless, several studies have concluded that social integration of people with intellectual disabilities is not convincingly achieved, especially for people with high support needs (e.g. Chowdhury & Benson, 2011; den Daas et al., 2007; Mansell, 2006; van Gennep & Ruigrok, 2002). As a potential solution for this problem, reversed integration was realised in the Netherlands. Because of the adapted environment and the deliberate choice of people without intellectual disabilities to live in such a neighbourhood, the assumption was that there were better opportunities for people with intellectual disabilities to become socially integrated. However, so far this assumption does not seem to hold.

Two aspects may play a large role in failing the social integration process of people with intellectual disabilities so far. First, when defining the meaning of the term (social) integration the severity of intellectual disabilities and the degree of behaviour problems was not taken into account. In neighbourhoods, social contacts are typically short verbal conversations in which there is some sort of reciprocity, such as both parties greeting each other (van Alphen et al., 2010; Bos, 2015; Bredewold, 2014; Johnson, Douglas, Bigby & Iacono, 2012). Especially for people with high support needs, however, such reciprocal social contacts are difficult to realize because they communicated primarily non-verbally (van Alphen et al., 2010; Bigby, Clement, Mansell & Beadle-Brown, 2009), and/or they had poor adaptive and social skills (Mansell, 2006). Yet, despite these disabilities, they can still be part of the community

and integrate within their own possibilities. For example, people with severe or profound intellectual disabilities already experience a sense of belonging by being in close proximity of people without intellectual disabilities (Vlaskamp & Verkerk, 2000). Therefore, in the debates about the meaning of terms like integration and inclusion, more attention should be paid to differences between people with intellectual disabilities and to their specific possibilities. Therefore, the suggestion is to define integration for every target group in the support of people with intellectual disabilities separately. Moreover, this definition can be specified for every individual so that realistic goals can be formulated. Thereby, a distinction can be made in the feasible expectations and it can be avoided that due to experiencing frustration when striving for unrealistic goals, DSPs and family members may reduce their efforts to facilitate integration of people with intellectual disabilities.

Second, as stated before, DSPs play an important role in the social integration process of people with intellectual disabilities (van Alphen, 2011; Chowdhury & Benson, 2011; Mansell, 2006; Mansell et al., 2002; Overmars-Marx, 2011). Their attitude is the most important determinant of the outcome of the social integration process. However, at the moment, DSPs' attitude and efforts are not in favour of social integration. Moreover, related to their experienced responsibility concerning safety (McConkey & Collins, 2010), DSPs may not be willing to give the people with intellectual disabilities sufficient opportunity to learn from contact with others. Therefore, to stimulate the social integration process of people with intellectual disabilities, first of all, one has to start with changing the attitudes of DSPs. If DSPs remain negative, social integration of people with intellectual disabilities will hardly occur. Another point of concern is the discrepancy between the perceived social norms of DSPs and the actual social norms of particularly the neighbours. DSPs could obstruct their own efforts to facilitate social integration of their clients by wrong ideas about the opinion of other stakeholders. More knowledge is needed about the causes and consequences of these discrepancies for social integration of people with intellectual disabilities. This knowledge may prevent other discrepancies between stakeholders in the future.

7.4 Practical Implications

Based on the results, there are several implications for practice. First of all, organisations who are responsible for the support of people with intellectual

disabilities need to be convinced of the importance of social integration before changes can be made. Besides, they should have a clear vision on social integration of people with intellectual disabilities. Currently, reversed integration does not bring the outcomes which were expected initially. Therefore, organisations need to consider what can be achieved with reversed integration for every target group separately and how DSPs should work to accomplish these goals. This should be elaborated in their policy statements, which gives the DSPs a framework to work with and it gives the stakeholders more clearance about the expectations. In their policy statement, attention should be paid to the role of DSPs. Currently, a large amount of work is expected from DSPs concerning social integration. However, as discussed, it is uncertain if it is reasonable to expect that they can accomplish all these tasks. Therefore, it might be necessary to reconsider the role of DSPs, for example, by decreasing the responsibilities for DSPs in volunteer work regarding social integration. In these tasks they can be replaced by, for example, a volunteer coordinator. On the other hand, organisations could also give DSPs more time to invest in activities that enhance social integration. Besides, agreement is required about the responsibility in situations in the neighbourhood when something goes wrong. This agreement should give the DSPs some protection against claims. Moreover, such an agreement could give the DSPs more space to explore the opportunities of social integration of people with intellectual disabilities.

Besides the role of DSPs, the role of volunteers in the social integration process also needs further clarification. Organisations could consider if they want their volunteers to perform tasks to enhance social integration, and if so, how this role for volunteers should look. With the current movement in the society concerning volunteer work in general, it is expected that there will be a shortage of volunteers in the support of people with intellectual disabilities. Therefore, organisations may consider the recruitment of new groups of volunteers (e.g. 'obligatory' volunteers, volunteers for one time volunteer work, and clients with mild or moderate intellectual disabilities as volunteers) to increase the number of volunteers.

Finally, meetings could be organised for all stakeholders to discuss their perspectives regarding social integration. The gap between the perceived perspectives and the actual perspectives that we observed in our studies could be discussed and tackled on these occasions. The expectation is that such meetings will positively influence the attitudes of DSPs towards integration of people with

intellectual disabilities and will positively influence their willingness to invest effort herein.

7.5 Recommendations for future research

The present dissertation provided valuable knowledge about the perspectives of the relevant stakeholders in a reversed integration neighbourhood regarding social integration of people with intellectual disabilities, and regarding the roles of formal and informal support in enhancing such integration. However, there are certainly still some gaps to fill in knowledge about reversed integration and the social integration process in this setting.

Firstly, this research took place after reversed integration was realised. To investigate the influence of such an environment on the quality of life of the people with intellectual disabilities, on the work of DSPs, and especially on the social integration process of the people with intellectual disabilities, an effect study is needed. Such a study would necessarily start before the change to reversed integration is made. Moreover, to investigate the changes over time in perspectives and in the contact between people with and without intellectual disabilities, a longitudinal design is mandatory. Such a setup would allow to further consolidate and enrich the findings from the present research.

Second, volunteer work in the support of people with intellectual disabilities is still an under-researched topic. There is much to investigate, such as the characteristics of the volunteer work in other countries. In the context of the present research, it would be especially relevant to investigate the actual and possible role of volunteers in enhancing social contacts between people with and without intellectual disabilities. This knowledge would help organisations to more effectively recruit volunteers in order to enhance social integration. Another topic which needs further attention is the question how specific groups of volunteers can be best reached by organisations. Knowledge on the specific motivations but also barriers that these new groups, for example clients, or people who are obligated to do volunteer work, may help to improve recruitment, to enhance work satisfaction and to reduce dropouts.

The present dissertation focused on the role of both formal and informal support in the social integration process of people with intellectual disabilities. Of course, this valuable knowledge is necessary but not enough to optimise the whole social integration process. A next step will be to focus on the people with intellectual

disabilities themselves: what are their needs and wishes? Are their differences between target groups and if so, what are these differences? It is important to also focus on the current social interactions of people with intellectual disabilities and, associated with that, on their desired ways to communicate. For example, Johnson et al. (2011) found that people with severe intellectual disabilities preferred having fun (routines and comedic interactions) and hanging out (contact and presence) in their social interactions. Knowing how to optimise the social interactions of people with intellectual disabilities can help to improve their interactions between people with and without intellectual disabilities.

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Summary

Since the 1960s many people with intellectual disabilities moved from residential facilities to living arrangements in the community, with the aim of improving their quality of life. This movement to community living (i.e. deinstitutionalisation) is intended as a first step to social integration of people with intellectual disabilities. In the present research, social integration is defined as being part of the community in which the person with intellectual disabilities is appreciated and respected. Several studies have shown that community living was associated with better outcomes regarding the quality of life for people with intellectual disabilities than living in residential facilities. However, concerning the social integration process, large differences were found between different target groups. Especially people with high support needs, like people with profound or severe intellectual disabilities or people with intellectual disabilities and behaviour and/or psychiatric problems, had poorer outcomes and were generally the first people who moved back to the residential facilities. Reversed integration could be an opportunity for these groups to improve the outcomes of the social integration process. Reversed integration means that the grounds of the residential facility is turned into a regular neighbourhood. People with intellectual disabilities stay in the same house with the same direct support professionals (DSPs), however their houses become part of the neighbourhood where they live next to people without intellectual disabilities. An important possible asset of reversed as compared to regular integration projects for people with intellectual disabilities is that the neighbourhoods with reversed integration are (ideally) set-up with specific attention to the needs of people with intellectual disabilities, and that people without intellectual disabilities who live on the former grounds of a residential facility knew about the presence of people with intellectual disabilities before deciding to rent or buy a house in this neighbourhood. Consequently, the expectation is that there are better opportunities for people with intellectual disabilities to become socially integrated.

Whether or not reversed integration actually meets this ambitious goal is, however, an under-research topic. The present research therefore tries to fill in some gaps of knowledge about reversed integration, especially concerning the social integration of people with intellectual disabilities. More specifically, the aim of this dissertation is to get a better understanding of (1) the perspectives of all parties playing a relevant role in the social integration process of people with intellectual disabilities in the reversed integration neighbourhood (i.e. DSPs, neighbours and

family members), and of (2) the role of formal and informal support in enhancing the social integration of people with intellectual disabilities.

Concerning the perspectives of the relevant stakeholders, there is, as far as we know, no research that compared the perspectives of DSPs, neighbours and family members involved in the integration process of people with intellectual disabilities in integrated settings. There are a few studies that investigated the perspectives of one of these groups in integrated settings (van Alphen et al., 201; Bigby et al., 2009; Lundeby, 2010; McConkey & Collins, 2010; Robertson et al., 2005), but research on the perspectives of all stakeholders is lacking. We believe that understanding the different perspectives and experiences of all involved parties is essential when striving for the successful integration of people with intellectual disabilities.

The role of formal support in enhancing the social integration of people with intellectual disabilities, is – in principle - a well-researched topic (e.g. Chowdhury & Benson, 2011; Mansell et al., 2002). However, thus far this research did not investigate the psychological variables that could influence the efforts of DSPs to facilitate social integration. The present research attempts to fill this gap by trying to predict the DSPs effort for realising integration as a function of several psychological variables. To this end, it builds on psychological research regarding the link between attitudes and the corresponding behaviour (Ajzen, 1985; Artis & Smith, 2013; Fishbein & Ajzen, 1975; Rise et al., 2010; Marta et al., 2014; Vorauer, 2013; Zolait, 2014).

Concerning the informal support, this research focusses primarily on the volunteers, because in several studies has been found that family members are already heavily burdened with the care for their relative. In addition, they often either work or are already elderly (Brouns, Tap & Stam, 2013; Oudijk, De Boer, Woittiez, Timmermans & De Klerk, 2010); accordingly, they mostly do not have the capacity to further contribute to volunteer work. Nationally and internationally, there is little if any research done about volunteer work in the support of people with intellectual disabilities. Therefore, the present research provides relevant information about the current situation regarding volunteer work for people with intellectual disabilities, and the role of social integration herein.

In the following the content and main findings of the various chapters in this dissertation are described in more detail.

Chapter 1 is an introductory chapter which describes the research context and the basic theoretical background for the present dissertation.

Chapter 2 describes research about the perspectives of various stakeholders involved in the integration process of people with intellectual disabilities in a reversed integration neighbourhood. Semi-structured interviews were conducted with 28 DSPs, 25 family members and 25 neighbours, aimed at their attitude towards social integration in a reversed integration neighbourhood. Importantly, there were no explicit questions about safety in the interview. The results showed that safety concerns were important barriers for the social integration of people with intellectual disabilities. The topic of safety was spontaneously and repeatedly mentioned by all (except two) DSPs, and was also very prominent in interviews with family members; neighbours, however, were much less concerned about this issue. Three main themes were found in the statements touching upon the issue of safety: environmental aspects (e.g., traffic), client characteristics (e.g., behaviour problems) and working conditions (e.g., tasks of DSPs). The most often mentioned subthemes were the openness of the neighbourhood and traffic. In sum, the results indicated that in a setting of reversed integration, safety was still a highly relevant topic and of great concern for the DSPs and the family members. Moreover, DSPs were more concerned with controlling risks and keeping everybody safe than looking at the opportunities the new environment might offer, like enhancing social integration.

Chapter 3 focuses on DSPs and describes three different psychological determinants of their behavioural intentions to facilitate the social integration of their clients: their attitudes (the opinion of DSPs about integration), their perceived social norms (DSPs' expected opinion of the other stakeholders, i.e. neighbours and family members, about integration) and their meta-evaluations (DSPs' expected attitude of family members and neighbours regarding the DSPs and their work). Besides, the DSPs' perceived social norms and meta-evaluations of the neighbours and family members were compared with the actual social norms and evaluations of these groups. Semi-structured interviews were conducted with 28 DSPs working in a reversed integration neighbourhood, as well as 25 family members and 25 neighbours. The results on attitudes revealed that half of the DSPs interviewed were positive about integration, while the other half were negative or neutral. Concerning social norms, the DSPs expected neighbours to have neutral attitudes towards integration of people with intellectual disabilities, while in reality the neighbours were

very positive. More than half of the DSPs were uncertain about the family members' opinions regarding social integration. Asking the family members themselves, there was indeed quite some variation in their attitudes towards social integration.

Regarding the meta-evaluation, DSPs had a realistic and positive idea about how their work would be evaluated by family members and neighbours: both groups were indeed positive. A relevant conclusion from these findings is that DSPs efforts to strive for social contacts between their clients and neighbours could be facilitated and potentially enhanced by creating awareness of a supportive social norm in the neighbourhood.

Chapter 4 examines the role of five possible psychological variables on the (intended) efforts of DSPs to facilitate their clients' integration . These variables are: attitudes (their attitudes towards integration), social norms (their thoughts about whether other stakeholders (i.e. family members and neighbours) approve of integration), experienced competencies (their experienced competencies in an integrated setting), identity (their professional identity and assumed role as a DSP), and meta-evaluation (their beliefs about the opinions of other the stakeholders about them and their work). A structured questionnaire was filled in by 336 DSPs who were working in one of three different types of locations (a regular integration neighbourhood, a reversed integration neighbourhood and a residential facility). The results showed that overall the experienced competencies, role identity and meta-evaluation were positive. In contrast, the DSPs' attitude regarding their clients' integration and their respective assumed social norms were rather negative and/or sceptical. Moreover, we found that DSPs' efforts to facilitate their clients' integration was predicted by their attitude towards integration, their experienced competencies, their role identity, and their meta-evaluation. Moreover, the effect of assumed social norms of the relevant stakeholders on predicting the DSPs efforts for integration was indirect, namely mediated through attitudes. In conclusion, we can state that a large number of psychological variables has impact on the behavioural attitudes of DSPs. Accordingly, organisations responsible for the support of people with intellectual disabilities have various options to realise interventions that may stimulate their DSPs to make greater efforts to facilitate their clients' integration.

Chapter 5 gives insight in the current volunteer work in the support of people with intellectual disabilities, and in the possibilities concerning the recruitment and role of volunteers in the future. This was investigated by means of a questionnaire filled in

by 117 volunteers and an expert meeting with 17 people involved in the support of people with intellectual disabilities. The questionnaire assessed the characteristics of the volunteers and their volunteer work, their motivation, and typical tasks. During the expert meeting, the participants discussed three themes: (1) in the future, are there new types of volunteers that could be recruited for supporting people with intellectual disabilities? (2) Which role can volunteers play in social integration process of people with intellectual disabilities? (3) What would be an optimal environment for volunteers to perform their tasks? Results depicted a relatively stable picture of volunteers in the support of people with intellectual disabilities: like in the past, they are mostly female, not having a paid job or are retired, and do the volunteer work mostly driven by altruistic motives. In addition, the expert meeting revealed that not all participants experienced volunteer work as a feasible bridge for the social integration, they felt that social integration was not in reach for all people with intellectual disabilities, and that it would require support by a larger number of volunteers. Moreover, due to, amongst other things, ageing and an increase in number of working women, a shortage in volunteers was expected. To prevent such shortage more attention should be paid to recruit new types of volunteers, like people who want to acquire work experiences, client volunteers, and compulsory volunteers.

Chapter 6 focuses on the role of volunteers in the social integration process. Moreover, it specifically addresses the role of volunteers in the physical integration of people with intellectual disabilities, as this is an essential step to social integration. In a first study about this topic, an explorative inventory was executed on the current tasks of volunteers. Results showed that helping with group activities is mentioned the most. Furthermore, most volunteers were performing activities in the community which enabled the physical integration of people with intellectual disabilities. In a second study, using a questionnaire, 235 DSPs rated on a 5-point scale which tasks they considered being suitable for volunteers to perform. In this study we found that DSPs mostly believed that activities in the community were not suitable for volunteers. Another interesting outcome is that the level of intellectual disabilities did not affect evaluations regarding the suitability of tasks these volunteers could perform. An exception is the group of people with intellectual disabilities and behaviour and/or psychiatric problems; for this group, volunteers typically performed tasks inside the homes and tasks wherein clients were not involved.

Chapter 7 is the final chapter and contains a reflection on the main findings of this research. When introducing reversed integration projects, the assumption was that such an environment would present better opportunities for people with intellectual disabilities to become socially integrated. However, so far this assumption does not seem to hold. Two aspects may play a large role in the failing of the social integration process of people with intellectual disabilities thus far. First, there is a lack of a proper definition of what it means to realise social integration for people with different levels of intellectual disabilities. For example, social contacts in neighbourhoods are primarily verbal conversations in which there is some kind of reciprocity. However, especially people with severe or profound intellectual disabilities, who communicate mostly nonverbally and/or have limited adaptation or social skills, will experience difficulties with social contacts. We may therefore consider to define integration for each target group again, so that its specific possibilities are taken into account and the respective opportunities for integration can be defined. Second, DSPs play an important role in the social integration process of people with intellectual disabilities. Moreover, their attitude towards social integration is of utmost importance in the social integration process of their clients. However, at the moment, DSPs' attitude and efforts are not in favour of social integration. Relatedly, due to their perceived responsibility concerning their clients' physical safety, DSPs may not be willing to give people with intellectual disabilities sufficient opportunity to learn from contact with others. Therefore, to stimulate the social integration process of people with intellectual disabilities, it might be a wise start to try changing the DSPs' attitudes towards the integration of their clients. An important factor herein is informing the DSPs about the attitude of the neighbours regarding social integration, which is more positive than DSPs expected. This knowledge may, as mentioned above, result in creating more opportunities and situations in which contact between people with and without intellectual can take place.

For organisations who offer support to people with intellectual disabilities, the present findings suggest that it is relevant to first develop a clear vision on social integration and on reversed integration. In organisational policies, sufficient attention should be paid to the role of DSPs, to the feasibility of their tasks, and their responsibilities regarding social integration of people with intellectual disabilities. This could give the DSPs more space to explore the possibilities of social integration

of people with intellectual disabilities that integrated neighbourhoods may offer. Secondly, more attention should be paid to the role of volunteers. Organisations need to consider which role they want for volunteers, especially regarding social integration. Furthermore, to prevent shortage in volunteers, it may be worthwhile to consider focusing on new types of volunteers that may help in the support of people with intellectual disabilities.

In the future more research is necessary about the effects of reversed integration on the quality of life of people with intellectual disabilities. Moreover, it seems worthwhile to further investigate the effects of reversed integration on the work of DSPs and on the social integration process. Longitudinal research would be best, because it provides insight in the changes over time in the attitudes and experiences of all parties involved. Besides, little research has been executed regarding volunteer work in the support of people with intellectual disabilities. Future research could therefore be focussing on the role of volunteers in the social contacts between people with and without intellectual disabilities.

To conclude, this dissertation offered valuable knowledge about the perspectives of stakeholders regarding social integration and about the role of formal and informal support in enhancing social integration of people with intellectual disabilities. However, more knowledge is necessary to optimise the social integration process of people with intellectual disabilities. Herein, more attention to how people with intellectual disabilities themselves experience social integration would be highly relevant. Obviously, one-size-fits-all policies would not work. Rather, tailor-made policies specified for every target group, might be more promising. A lot is still to be done, but this dissertation hopefully made a substantial step towards a better understanding of the social integration of people with intellectual disabilities .

Samenvatting

Sinds de jaren 60 zijn veel mensen met een verstandelijke beperking verhuisd van residentiële voorzieningen naar woonvoorzieningen in de wijk, waarmee werd beoogd de kwaliteit van hun leven te verbeteren. De beweging naar het wonen in de wijk (deïstitutionalisatie) is een eerste stap richting sociale integratie van mensen met een verstandelijke beperking. Sociale integratie is in dit onderzoek gedefinieerd als 'het onderdeel zijn van de maatschappij waarbij de persoon met een verstandelijke beperking gewaardeerd en gerespecteerd wordt' (van Alphen, 2011; van Gennep & Ruigrok, 2002). Uit het literatuuronderzoek van Chowdhury en Benson (2011) komt naar voren dat verschillende onderzoeken hebben aangetoond dat het wonen in de wijk zorgt voor een betere kwaliteit van leven voor mensen met een verstandelijke beperking in vergelijking met het wonen in residentiële voorzieningen. Er blijken echter grote verschillen te zijn tussen de verschillende doelgroepen. Met name bij mensen met een grote ondersteuningsbehoefte zoals mensen met een (zeer) ernstige verstandelijke beperking en mensen met een verstandelijke beperking en gedrags- en/of psychiatrische problematiek, blijkt het integratieproces niet of amper plaats te vinden en zijn zij over het algemeen ook de eersten die weer terug worden geplaatst in de residentiële voorzieningen.

Omgekeerde integratie kan een mogelijkheid zijn om ook deze groep te betrekken in de gewenste richting van sociale integratie. Omgekeerde integratie betekent dat het terrein van een residentiële voorziening is omgevormd tot een woonwijk. Mensen met een verstandelijke beperking blijven in hetzelfde huis wonen en houden dezelfde begeleiders. Hun woningen zijn echter nu onderdeel van een woonwijk waar ze wonen naast mensen zonder een verstandelijke beperking. Een voordeel van omgekeerde integratie vergeleken met reguliere integratie is dat de woonwijk aangepast is aan de mensen met een verstandelijke beperking. Daarnaast waren de mensen zonder een verstandelijke beperking op de hoogte van de aanwezigheid van mensen met een verstandelijke beperking voordat ze besloten om een huis te kopen of huren in de woonwijk. De verwachting is dat mensen met een verstandelijke beperking in deze wijk betere mogelijkheden hebben om sociaal te integreren.

Omgekeerde integratie is echter een onderwerp waar tot op heden weinig onderzoek naar is gedaan. Dit onderzoek probeert daarom de kennis te vergroten over omgekeerde integratie, met name wat betreft de sociale integratie van mensen met een verstandelijke beperking. Meer specifiek is het doel van deze dissertatie om meer kennis te krijgen over (1) de perspectieven van de mensen die betrokken zijn

bij het sociale integratieproces van mensen met een verstandelijke beperking in een omgekeerde integratiewijk (begeleiders, omwonenden en verwanten) en (2) de rol van de formele en informele zorg bij het verbeteren van de sociale integratie van mensen met een verstandelijke beperking.

Wat betreft de perspectieven van alle direct betrokkenen (begeleiders, omwonenden en verwanten) is er, voor zover bekend, geen onderzoek dat de verschillende perspectieven op het leven van mensen met een verstandelijke beperking vergelijkt. De enkele onderzoeken die zijn uitgevoerd hebben het perspectief van één van de betrokken partijen onderzocht in geïntegreerde woonvoorzieningen (van Alphen et al., 2012; Bigby et al., 2009; Lundebj, 2010; McConkey & Collins, 2010; Robertson et al., 2005). Kennis over de verschillende perspectieven en ervaringen van alle direct betrokkenen is volgens ons essentieel bij het streven naar succesvolle integratie van mensen met een verstandelijke beperking.

Met betrekking tot sociale integratie is de rol van de formele zorg al vaak onderwerp van onderzoek geweest (bijv. Mansell et al., 2002; Chowdhury & Benson, 2011). Echter, hierbij is tot op heden niet gekeken naar de psychologische variabelen die invloed kunnen hebben op de inzet van begeleiders ter bevordering van sociale integratie. In dit onderzoek wordt getracht de inzet van begeleiders om sociale integratie te faciliteren te voorspellen aan de hand van verschillende psychologische variabelen. Deze variabelen komen voort uit psychologisch onderzoek dat een link legt tussen attitudes en gedrag (Ajzen, 1985; Artis & Smith, 2013; Fishbein & Ajzen, 1975; Marta et al., 2014; Rise et al., 2010; Vorauer, 2013; Zolait, 2014).

Naast formele zorg hebben we in ons onderzoek ook gekeken naar de rol van informele zorgverleners, in dit onderzoek beperkt tot de vrijwilligers. Deze beperking vloeit voort uit de resultaten van onderzoeken waaruit is gebleken dat de belasting van de verwanten vaak al hoog is en ze daarnaast werken of al op leeftijd zijn (Brouns, Tap & Stam, 2013; Oudijk, de Boer, Woittiez, Timmermans & de Klerk, 2010). Zij hebben over het algemeen niet de mogelijkheden om, naast de zorg voor hun familielid, zich ook in te zetten voor vrijwilligerswerk. Daarnaast is naar vrijwilligerswerk in de zorg voor mensen met een verstandelijke beperking is tot op heden nationaal en internationaal geen onderzoek verricht. Hierom is het belangrijk om eerst het huidige vrijwilligerswerk in kaart te brengen en vervolgens te

onderzoeken welke rol vrijwilligers kunnen spelen in het bevorderen van de sociale integratie.

Hieronder zullen de inhoud en de bevindingen van de verschillende hoofdstukken in deze dissertatie in meer details beschreven worden. In *hoofdstuk 1* wordt allereerst de context van het gehele onderzoek beschreven. Vervolgens wordt in *hoofdstuk 2* de attitude van verschillende direct betrokkenen met betrekking tot sociale integratie in een omgekeerde integratiewijk in kaart gebracht. Semigestructureerde interviews zijn gehouden met 28 begeleiders, 25 omwonenden en 25 verwanten met als doel om hun attitudes met betrekking tot sociale integratie in een omgekeerde integratiewijk in kaart te brengen. Verschillende onderwerpen zijn daarbij besproken zoals de buurt en het contact tussen mensen met een verstandelijke beperking en de omwonenden. Uit de resultaten bleek het gevoel van onveiligheid als een belangrijk obstakel voor sociale integratie van mensen met een verstandelijke beperking naar voren te komen. Het onderwerp werd spontaan 90 keer genoemd door 26 begeleiders, 15 keer door 9 omwonenden en 36 keer door 18 verwanten. Er waren geen expliciete vragen over veiligheid in het interview. In alle uitspraken die betrekking hadden op veiligheid waren drie hoofdthema's te onderscheiden: omgevingsaspecten (bv. verkeer), kenmerken van de cliënt (bv. gedragsproblematiek) en werkomstandigheden (bv. taken). De meest genoemde deelonderwerpen waren de gevolgen van het opheffen van de afbakening van het terrein, en de verkeerssituatie. De resultaten laten zien dat veiligheid binnen omgekeerde integratie een zeer relevant onderwerp is en tot grote zorgen bij de begeleiders en verwanten leidt. Bovendien zijn de begeleiders meer bezig met het onder controle houden van de veiligheidsrisico's en het garanderen van veiligheid voor iedereen dan dat ze kijken naar de mogelijkheden die de omgeving biedt. Met name aan de mogelijkheden met betrekking tot het verbeteren van sociale integratie zouden begeleiders meer aandacht kunnen besteden.

Hoofdstuk 3 richt zich op begeleiders en beschrijft drie verschillende psychologische determinanten van de intenties van begeleiders om hun cliënten te ondersteunen bij sociale integratie, namelijk attitude (de mening van begeleiders over integratie), sociale norm (wat begeleiders denken dat de andere betrokkenen (omwonenden en verwanten) vinden van sociale integratie) en meta-evaluatie (de gedachten van de begeleiders over hoe er tegen henzelf en hun werk aangekeken

wordt door de verwanten en omwonenden). De door begeleiders verwachte sociale norm en meta-evaluatie zijn vergeleken met de werkelijke sociale norm en evaluatie van omwonenden en verwanten. Semigestructureerde interviews zijn afgenomen bij 28 begeleiders, 25 omwonenden en 25 verwanten. De resultaten met betrekking tot de attitude laten zien dat de helft van de begeleiders positief is over sociale integratie, terwijl de andere helft negatief of neutraal is. Wat betreft de sociale norm verwachten de begeleiders dat de omwonenden een neutrale attitude hebben over integratie, terwijl in werkelijkheid de omwonenden erg positief zijn. Meer dan de helft van de begeleiders weet niet wat de verwanten vinden van integratie. Uit de interviews met de verwanten komt ook naar voren dat er behoorlijk variatie zit in hun attitude met betrekking tot integratie. Wat betreft de meta-evaluatie hebben de begeleiders een realistisch beeld van hoe hun werk beoordeeld wordt door de omwonenden en verwanten: beide groepen zijn positief. Door de begeleiders bewust te maken van het feit dat omwonenden veel positiever zijn over sociale integratie dan zij verwachten, kan het ze helpen en aanmoedigen om te streven naar sociale contacten tussen hun cliënten en de omwonenden.

In *hoofdstuk 4* wordt de rol van vijf psychologische variabelen in de inzet van begeleiders om de integratie van hun cliënten te faciliteren, onderzocht⁶. De variabelen zijn: attitude (hun positieve of negatieve mening over de integratie van hun cliënten in de maatschappij), sociale norm (hun gedachten over wat de andere betrokkenen, d.w.z. omwonenden en verwanten, vinden van pogingen tot integratie), ervaren competenties (hun ervaren competenties in een geïntegreerde setting), identiteit (hun professionele identiteit en hun verwachte rol als begeleider) en meta-evaluatie (hun gedachten over hoe er tegen henzelf en hun werk aangekeken wordt door de andere betrokkenen). Een gestructureerde vragenlijst is ingevuld door 336 begeleiders die werkzaam zijn op één van de drie type locaties (residentiele voorziening, omgekeerde integratie woonwijk en reguliere woonwijk). De resultaten laten positieve uitkomsten zien op de ervaren competenties, de rolidentiteit en de

⁶ In hoofdstuk 4 wordt gesproken over inclusie, wat als equivalent is gebruikt van integratie (Clement & Bigby, 2009). Deze veronderstelde conceptuele equivalentie bestaat in de orthopedagogische context, maar niet in dezelfde mate in de psychologische context. In deze context is de recente definitie van inclusie: “De mate waarin het individu ervaart dat de groep hem of haar het gevoel geeft van authenticiteit en erbij te horen (Jansen, Otten, van der Zee & Jans, 2014). Hierin is de focus meer op de psychologische ervaring van inclusie, wat maakt dat het concept geen equivalent is van integratie maar eerder een onderdeel ervan. Dit is nauw verwant is aan de beschrijving van psychologische integratie (de Vroome & Verkuyten, 2015). Voor de consistentie wordt hier in de samenvatting het begrip integratie aangehouden.

meta-evaluatie. Daarentegen waren de resultaten met betrekking tot attitude van begeleiders over integratie en hun verwachte sociale norm, relatief negatief en/of sceptisch. De conclusie uit dit onderzoek is dat de inzet van begeleiders om de integratie van hun cliënten te faciliteren, afhankelijk is van hun attitude ten opzichte van integratie, hun ervaren competenties, hun rolidentiteit, hun meta-evaluatie en indirect via de attitude, de verwachte sociale norm van de overige betrokkenen. Organisaties die verantwoordelijk zijn voor de ondersteuning van mensen met een verstandelijke beperking en die willen dat de begeleiders meer inzet tonen om de integratie te faciliteren, zouden aandacht moeten besteden aan één of meerdere van deze psychologische factoren.

Hoofdstuk 5 geeft inzicht in het huidige vrijwilligerswerk in de zorg voor mensen met een verstandelijke beperking, en in de mogelijkheden wat betreft de werving en de rol van de vrijwilligers in de toekomst. Dit is op twee manieren onderzocht. Allereerst is een vragenlijst afgenomen bij de vrijwilligers op de betrokken locaties, die werd ingevuld door 117 vrijwilligers. De vragenlijst bestond uit vragen over de kenmerken van de vrijwilliger en het vrijwilligerswerk, de motivatie en hun taken. Ten tweede werd een expertmeeting georganiseerd waar 17 mensen aan hebben deelgenomen die betrokken zijn bij de ondersteuning van mensen met een verstandelijke beperking (mensen uit het management van de organisatie, professionals, verwanten en vrijwilligers). Tijdens de expertmeeting is gediscussieerd over drie thema's: (1) welke nieuw type vrijwilligers kan aangetrokken worden voor het ondersteunen van mensen met een verstandelijke beperking? (2) Welke rol kunnen vrijwilligers spelen in het bevorderen van de sociale integratie van mensen met een verstandelijke beperking? (3) Wat zou een optimale context zijn voor vrijwilligers om hun taken uit te voeren? De resultaten laten zien dat de vrijwilligers voornamelijk de 'traditionele' vrijwilligers zijn, dat wil zeggen: vrouwen die geen betaalde baan hebben, of al gepensioneerd zijn, en die het vrijwilligerswerk doen vanuit altruïstische motieven. Uit de expert meeting komt naar voren dat niet alle betrokkenen vrijwilligerswerk zien als een manier om sociale integratie te verbeteren. Sociale integratie wordt bovendien niet voor alle mensen met een verstandelijke beperking haalbaar geacht, met name voor mensen met een intensieve zorgvraag oordeelt men niet positief over de haalbaarheid. Om vrijwilliger in te kunnen zetten om de sociale integratie te bevorderen, zijn er bovendien voldoende vrijwilligers nodig. Door onder andere vergrijzing en toename van werkende vrouwen, wordt een

tekort aan het 'traditionele type' vrijwilligers verwacht. Om dit te voorkomen, zal er in de werving aandacht moeten komen voor nieuwe type vrijwilligers, zoals mensen die werkervaring op willen doen, cliënt vrijwilligers en geleide vrijwilligers.

Hoofdstuk 6 beschrijft het onderzoek naar de rol van vrijwilligers in het sociale integratie proces. Hierbij wordt specifiek gefocust op hun rol binnen de fysieke integratie, omdat dit een noodzakelijke stap is naar sociale integratie. In studie I is een explorerende inventarisatie uitgevoerd om de huidige taken van vrijwilligers in kaart te brengen. Uit deze studie blijkt dat helpen bij groepsactiviteiten het meest wordt gescoord. Daarnaast komt naar voren dat de meeste vrijwilligers momenteel taken uitvoeren in de maatschappij waardoor fysieke integratie van mensen met een verstandelijke beperking mogelijk wordt gemaakt. In studie II hebben begeleiders door middel van een vragenlijst gescoord op een 5-puntsschaal in hoeverre zij taken geschikt vonden voor vrijwilligers. De resultaten laten zien dat de meest begeleiders van mening zijn dat taken die uitgevoerd worden in de maatschappij, niet geschikt zijn voor vrijwilligers. Een ander opvallende uitkomst is dat het niveau van de verstandelijke beperking geen rol lijkt te spelen bij het bepalen van de geschiktheid van bepaalde taken voor de vrijwilligers. Alleen mensen met een verstandelijke beperking en gedrags- en/of psychiatrische problematiek lijken wat betreft de fysieke integratie, niet te profiteren van vrijwilligers. De vrijwilligers bij deze doelgroep doen momenteel met name niet cliëntgebonden taken in de woonvoorziening en ook de begeleiders vinden taken die uitgevoerd worden in de woonvoorziening het meest geschikt voor deze vrijwilligers.

Hoofdstuk 7 is het laatste hoofdstuk en bevat een reflectie op de belangrijkste resultaten uit het onderzoek. Bij het ontwikkelen van de omgekeerde integratie projecten was de verwachting dat in deze woonwijken de mensen met een verstandelijke beperking betere mogelijkheden zouden hebben om sociaal te integreren. Tot op heden lijkt deze verwachting echter niet waar gemaakt te worden. Hiervoor zijn twee mogelijke verklaringen. Ten eerste ontbreekt een goede definitie van wat sociale integratie inhoudt voor mensen met verschillende niveaus van verstandelijke beperking. Sociale contacten in een wijk zijn bijvoorbeeld over het algemeen verbale contacten waarbij er sprake is van een zekere wederkerigheid. Voor met name mensen met ernstige of zeer ernstige verstandelijke beperking, die voornamelijk non-verbaal communiceren en/of beperkte aanpassings- en sociale vaardigheden hebben, zijn sociale contacten moeilijk. Om ook deze mensen een

kans te geven om sociaal te integreren, dient er rekening gehouden te worden met de mogelijkheden van en verwachtingen bij alle betrokkenen. We stellen daarom voor om sociale integratie voor iedere doelgroep opnieuw te definiëren, zodat er rekening gehouden kan worden met ieders mogelijkheden om te integreren. Ten tweede spelen begeleiders een belangrijke rol in de sociale integratieproces van mensen met een verstandelijke beperking. Hun attitude met betrekking tot sociale integratie is hierbij uitermate belangrijk. Echter, momenteel is de attitude van de begeleiders niet positief evenals hun inzet om de sociale integratie te bevorderen van hun cliënten. Een belangrijke factor hierbij is dat ze verantwoordelijkheid ervaren voor de fysieke veiligheid van hun cliënten waardoor ze hun cliënten nauwelijks de kans lijken te geven om te leren in het contact met omwonenden. Om sociale integratie te bevorderen is het daarom allereerst belangrijk om de attitude van de begeleiders positief te veranderen. Een belangrijke factor hierin zou kunnen zijn om de begeleiders beter te informeren over de attitudes van de omwonenden, die in feite veel positiever is dan van hen verwacht. Deze kennis zou dan, zoals verder boven al geredeneerd, tot meer openheid voor het creëren van contactsituaties kunnen leiden.

De aanbeveling aan organisaties in de zorg voor mensen met een verstandelijke beperking is ten eerste om een duidelijke visie te ontwikkelen op sociale integratie en op omgekeerde integratie. In het daarop afgestemde beleid zou allereerst aandacht besteed moeten worden aan de rol van begeleiders, de uitvoerbaarheid van hun taken en hun verantwoordelijkheden met betrekking tot sociale integratie van hun cliënten. Duidelijk beleid geeft begeleiders onder andere meer ruimte om te kijken naar de mogelijkheden voor sociale integratie van mensen met een verstandelijke beperking. Ten tweede zou in het beleid meer aandacht besteed moeten worden aan de rol van vrijwilligers. Organisaties zouden moeten overwegen welke rol zij weggelegd zien voor vrijwilligers bij het bevorderen van de sociale integratie. Daarnaast zouden ze het werven van nieuwe type vrijwilligers kunnen overwegen om een tekort aan vrijwilligers te voorkomen.

In de toekomst is meer onderzoek naar de effectiviteit van omgekeerde integratie op de kwaliteit van leven van mensen met een verstandelijke beperking noodzakelijk. Ook de invloed van omgekeerde integratie op het werk van de begeleiders en op de sociale integratie van mensen met een verstandelijke beperking zou onderzocht moeten worden. Onderzoek zou bovendien longitudinaal moeten zijn, opdat

veranderingen in perspectieven en ervaringen van de directe betrokkenen zoals begeleiders, omwonenden en verwanten op lange termijn duidelijk worden. Daarnaast is er tot op heden weinig onderzoek verricht naar vrijwilligerswerk in de zorg voor mensen met een verstandelijke beperking. Toekomstig onderzoek zou zich kunnen richten op de rol van vrijwilligers bij het bevorderen van sociale contacten tussen mensen met en zonder een verstandelijke beperking.

Dit proefschrift heeft waardevolle kennis opgeleverd over de perspectieven van begeleiders, omwonenden en verwanten met betrekking tot integratie van directe betrokkenen in het leven van mensen met een verstandelijke beperking in een omgekeerde integratiewijk. Daarnaast is er dankzij dit onderzoek meer duidelijkheid over de rol van de formele en informele zorg in het bevorderen van de sociale integratie van mensen met een verstandelijke beperking. Meer kennis is echter nodig om het sociale integratieproces van mensen met een verstandelijke beperking te optimaliseren. Hierbij is het belangrijk dat er aandacht besteed wordt aan hoe mensen met een verstandelijke beperking zelf de sociale integratie ervaren. Daarnaast zal één algemeen beleid waarschijnlijk niet werken, terwijl een passend beleid voor elke doelgroep veelbelovend zou kunnen zijn. Er is nog veel onderzoek te verrichten naar dit onderwerp, desalniettemin heeft deze dissertatie hopelijk een aandeel geleverd in het beter begrijpen van de sociale integratie van mensen met een verstandelijke beperking.

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About the author

Eleonora Venema was born in 't Zandt in 1989. In 2007, she received her gymnasium diploma from the Willem Lodewijk Gymnasium in Groningen. She studied orthopedagogy at the University of Groningen, with the specialisations youth care and support of people with disabilities. During her bachelor she participated in, and completed the honours programme, a project for excellent students to gain experience with scientific research. Her assignment during the two-year honours programme was to research multi-sensory storytelling, a storytelling method for people with profound intellectual and multiple disabilities. After receiving her master degree, she worked as a psychologist at GGZ Drenthe in the child and adolescent psychiatry. In 2012 she began a two-year research into social integration in a reversed integration neighbourhood. Eventually, the research was extended to a PhD of three-and-a-half years. Currently, she is doing the post master education of health care psychologist.

